Visitor Restrictions during a Public Health Emergency: Ethical Issues and Guidelines for Policy Development[1]

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[1] The opinions expressed herein are those of the authors and do not necessarily reflect those of the organizations for whom they are employed.

During the SARS crisis, the Ministry of Health and Long Term Care issued directives to hospitals and long term care facilities instructing them to restrict the number of visitors to their sites. This included facilities with and without any identified exposure to SARS, in and outside of the Greater Toronto Area. The visitor restrictions that emerged in response to the ministry directives varied widely from site to site and created considerable angst for patients, visitors, staff, and the general public. In this discussion paper, the specific issues and concerns that arose as a result of the directives and the associated facility policies on visitor restrictions are identified and described. The underlying ethical values and value conflicts are examined. We conclude with recommendations for visitor restrictions during future public health emergencies that attempt to minimize harms and maximize benefits for patients, visitors, staff, and the general public. Although the proposed policy guidelines were developed in response to the experiences of healthcare providers during the SARS crisis, they are broad enough to apply in the context of any public health emergency related to an infectious disease outbreak.

Methodology

A consistent methodology was used to analyze the issues and underlying ethical values and value conflicts that arose around visitor restrictions during SARS and to suggest practical approaches for developing and implementing policies related to visitor restrictions in case of future public health emergencies. Towards this end we relied heavily on the methodology of Philosopher/Theologian Bernard Lonergan (1973). His work on method provides a series of steps that move from experience, to understanding, to judgment and on to decision or action. His method is appropriate with regard to this

topic as it focuses on the experiences of the human person who struggles to do good. The struggle to do good was acutely evident throughout the SARS crisis as health care providers and institutions sought to keep the needs of individual patients at the forefront as they coped with competing demands and conflicting values in the context of a constantly changing and uncertain environment.

We began by looking at the experiences of health care workers and institutions related to visitor restrictions by gathering and reviewing the following data:

1. Summaries of the submissions by individuals, organizations, and facilities to the Campbell Commission; and
2. Responses to the questionnaire sent out by the Expert Panel on SARS and Infectious Disease Control.

Through a thematic analysis of these texts, three recurring and important issues relating to visitor restrictions emerged as follows:

1. Detrimental Psychosocial Impact
2. Communication Breakdowns
3. Wide and Varied Interpretation and Implementation of Ministry Directives

Each of these will be described in greater detail below.

Issues and Concerns

Detrimental Psychosocial Impact

Healthcare providers expressed considerable concern about the detrimental psychosocial impact of visitor restrictions that was most heavily felt by patients and their loved ones. Patients who were imminently dying, patients who were terminally or critically ill, pediatric patients, patients who were experiencing a significant life event

(e.g., birth of a child), and patients who were hospitalized for extended lengths of time were among those who suffered emotionally, psychologically, and socially.[2] Additionally, patients whose ability to understand what was happening to them was limited due to language or other communication barriers or as a result of decreased capacity, as was the case with many residents in long-term care, also endured the effects of social isolation. As one respondent to the questionnaire stated, "it was not insignificant for long-term care that the SARS crisis coincided with several important cultural and family-centered dates: Easter, Passover, Mother's Day and Father's Day." Family members and friends who were unable to visit loved ones experienced fear and anxiety about patients' safety and well-being. Some family members made personal appeals to hospital chief executive officers, as well as to municipal, provincial, and federal politicians pleading that exceptions be made to visitor restrictions. Although not reported by respondents to the questionnaire, anecdotally, many health care providers raised concerns that individuals who were labelled as suspect or probable SARS cases, and anyone who was in contact with the individuals (including healthcare providers), often felt ostracized and alone.

Communication Breakdowns

As information flowed from one party to another (i.e., from Ministry to general public; from Ministry to facilities; from facilities to staff, patients and visitors; and from staff to patients and visitors), communication breakdowns were experienced. This was compounded by the perception that directives issued by the Ministry were confusing or

[2] Anecdotally, there were a few obstetrical patients who expressed relief at not having to entertain large numbers of visitors post-delivery. However, the overwhelming majority of patients and family members found the visitors restrictions to be emotionally challenging.

conflicting and that the rationale for putting forward a particular visitor restriction was either unclear or altogether absent. Many staff, patients, and visitors experienced the visitor restrictions as arbitrary, and some chose not to comply. According to one respondent, "The public did not comply with visiting policies. We had to hire extra security. Public was down right nasty at times." A plethora of information around visitor restrictions was received by facilities, but facilities were often unable to process or uniformly communicate the information to staff, patients, and visitors in a timely and comprehensive manner. Similarly, directions to staff on how and what information to communicate to patients and visitors were lacking. Thus the same information was often communicated differently by different people and to different groups throughout a single organization. The volume and frequency of new directives issued to facilities was reported as overwhelming, and directives often arrived late in the evening or late in the week. This contributed to the confusion and to the inability to communicate adequately with staff, patients, and visitors. As stated by one respondent, and reflected in the comments of others, "many were not aware of restrictions until they came to hospital." Only limited information about visitor restrictions was communicated from the Ministry to the general public and certain groups of individuals, such as the homeless or non-English speaking persons, had almost no access to information about visitor restrictions released by either the Ministry or facilities. The communication breakdowns contributed to a sense of chaos and distress for everyone.

Wide and Varied Interpretation, Implementation, and Response to Ministry Directives

Facilities reported being allowed to use a certain amount of discretion in the development and implementation of visitor restrictions. Consequently, there were substantial variations in visitor restrictions from site to site. As one respondent indicated, "the rationale for restricted visiting was difficult to transmit to the public and this was confounded by the wide variation in visiting policies that emerged when the directives became more liberal." The decision to severely restrict visitors in response to an infectious outbreak was viewed quite differently by staff. For some staff, the visitor restrictions were received quite positively with many proposing a more restrictive approach on a permanent basis. As one respondent stated, "We realize that it is in the best interest of the patient to have family present during their stay, however in the last few years the H on the top of the hospital has become an H for hotel. The visiting policies in all hospitals need revisions and restrictions added. Infection prevention is utmost and will not be allowed to happen when staff must cope with numerous visitors impeding and preventing proper medical care. Visitors can be a prime source of infection." Other staff were angered by the restrictions and found them difficult and labour intensive to implement. Still others expressed concern that the "no visitor policy created extreme emotional distress" for patients, visitors, and staff.

Document Review

Given that the experiences focused largely on concerns about Ministry directives and facility communications related to visitor restrictions, it was necessary to review a sampling of these original documents in order to further inform our understanding and

analysis. Ministry directives issued between March 27, 2003 and October 22, 2003 were examined. Similarly, facility communications related to visitor restrictions from that same time period were reviewed. Our review of facility communications was limited to a small sample of acute care and chronic care facilities. We found inconsistencies between the two sets of documents that help, in part, to explain why these experiences arose. Inconsistencies between Ministry directives and facility communications were evident in the following areas: content, timing, and interpretation.

For example, at one time point a Ministry directive recommended discontinuation of visitor restrictions and balancing the need for visitation with patient's healthcare needs. In response, one facility indicated that "a one visitor at a time" policy was to remain in effect. Another institution noted that the Ministry directive had changed, but chose not to implement the directive until a later date due to staffing issues. Yet another institution maintained a no visitor policy indicating that the balance should still be tipped in favour of the patient's healthcare needs above the need for visitation. Even when the Ministry directive required a no visitor policy, the Ministry still permitted visitors on compassionate grounds. However, there were striking inconsistencies noted in the way in which various facilities interpreted what constituted compassionate grounds for visitation, particularly in the way in which patients were categorized as imminently dying, critically ill, or palliative.

Underlying Ethical Values and Conflicts

A group from the University of Toronto Joint Centre for Bioethics identified ten ethical values that ought to influence decision makers who enter into the "balancing act" that is required in weighing competing goods in future public health emergencies

(Upshur, 2003). These values included individual liberty, privacy, protection of the public from harm, protection of communities from undue stigmatization, proportionality, duty to provide care, reciprocity, equity, transparency, and solidarity. The experience of healthcare providers and the issues that emerged around the detrimental psychosocial impact, communication breakdowns, and wide and varied interpretation, implementation, and response to Ministry directives point to areas of conflict relative to many of these values. An understanding of these areas of conflict is a necessary prior step to providing ethically justifiable recommendations relative to visiting policies in future public health emergencies.

Detrimental Psychosocial Impact

Visiting restrictions impacted individual liberty by limiting the ability of persons to move about freely. These restrictions were experienced as unnecessarily restrictive by patients, visitors, and staff, particularly when there was little or no evidence of potential or actual risk. In our judgment, during the SARS crisis the level of restrictions placed on individuals appeared in some instances to be disproportionate to the risk of harm to the public.[3] While there are situations in which restrictions of liberty may be legitimate, these should be proportionate to the potential harm that one is attempting to avoid. The value of individual liberty was, we believe, on occasion unnecessarily trumped in favour of

[3] The benefits of visitation for hospitalized patients, including those in intensive care units, are generally supported in the literature. These benefits include reducing patient anxiety and promoting patient's health (Giganti, 1998; Mason, 2000; Messner, 1996). In a recent post-SARS survey of restricted visiting at Ottawa Hospital by Quinlan, Loughrey, Nicklin, and Roth (2003), staff, patients, and next of kin reported general satisfaction with limiting the number of visitors and hours of access. However, at this hospital, patients were allowed two visitors per day for a period of 5 hours. This represents considerable more visitor access than was allowed at most hospitals in the greater Toronto area. Further study of the impact of visitor restrictions in general and in the context of a public health emergency is needed and will be important in guiding the development of visitor policies.

protection of the public from harm. In implementing the early directives that did not allow for any visitors, the patients who arguably had the greatest need for visitor contact (e.g., imminently dying, terminally and critically ill patients, pediatric patients, labouring mothers, patients undergoing serious or significant procedures/treatment, non-English speaking patients and those with other communication barriers, incapable persons, long-term care residents) suffered disproportionate harms. This resulted in an inequitable situation. We saw a slight movement towards a more appropriate proportion of harm reduction measures to individual liberty with the later directives related to visitation which moved from an absolute "no visitor" directive to a "no visitor" directive which allowed for visitation in exceptional cases. We recognize that some degree of visiting restrictions is necessary and that the level of restriction may need to be increased as risk elevates. However, if this arises there needs to be a reciprocal response by facilities that is locally and provincially supported to mitigate the harms. This should occur in all situations where visitors are restricted. It may be especially important for those patients who are suspect or probable cases of the infectious disease in question. As mentioned previously, patients who were suspect or probable SARS and their contacts experienced feelings of ostracization and abandonment. The reciprocal responses should include measures such as telephone access for all patients, provision of care packages to patients, facilitation of communication between patients and significant others (e.g., e-mail, photographs), and maintaining the availability of health professionals such as hospital chaplains, social workers, psychologists, and ethicists (some of whom were declared unessential and told to stay at home during the previous SARS crisis).

Communication Breakdowns

The lack of consistency in communication of directives relative to visitors resulted in an uneven and inequitable approach throughout the health care system. As a result, staff, patients and visitors were left with the sense that they had been unfairly treated. While no doubt this was not the intent of those writing the directives or those attempting to communicate them, the ensuing result was the same. As described previously, healthcare providers did not believe that the rationale for visitor restrictions was clearly articulated. They also found that the information provided was conflicting and that the volume and timing of directives resulted in a situation in which many did not feel adequately informed. In a public health emergency, there is a need for transparency in providing timely, relevant, and comprehensive information about all issues including those related to visitor restrictions. Without transparency and a sufficient understanding of the risks and benefits associated with allowing visitors in facilities, it was difficult for facilities to produce coherent internal communications. The lack of transparency regarding the rationale for the restrictions contributed to a perception that the restrictions were arbitrary and as a result there were instances of non-compliance by visitors. Non-compliance of visitors resulted in the public being labelled by some healthcare providers as "nasty." Two important caveats to transparent communications is that they are sensitive to the potential of unduly stigmatizing specific communities and that the privacy of personal information is maximally protected.

Wide and Varied Interpretation, Implementation, and Response to Ministry Directives

The level of flexibility that was inherent in the directives without corresponding rationale to assist facilities in their interpretation and implementation created a situation in which there was significant variation in visitor restrictions within and across facilities. Many institutions chose the default position and enacted the most restrictive measures rather than the least restrictive. This default position was likely due to a desire to keep staff and patients safe, as well as a growing inability on the part of institutions to cope with the medical situation and concurrently respond to an influx of visitors. However, in a number of instances there was a significant imbalance between the potential for risk and the restrictions put in place. As a result, the interpretation of the directives sometimes resulted in a "no visitor" policy for patients in level 0 institutions. Such instances clearly do not meet the ethical requirement of proportionality. The wide and varied interpretation and implementation of directives resulted in a number of inequitable situations. In some facilities the interpretation of what constituted the "imminently dying patient" or "exceptional cases" resulted in situations in which certain patients did not see their families for many weeks, where patients died without their loved ones present, where children did not have the benefit of having both parents visit, where women laboured alone without their partners and where the confused geriatric patients wondered why no-one came to see them on Mother's Day or Father's Day.

Summary and Recommendations

In our analysis of the data, three themes around visitor restrictions clearly emerged: detrimental psychosocial impact, communication breakdowns, and wide and varied

interpretation, implementation, and response to Ministry directives. In examining the underlying ethical values and conflicts, we identified several ethical values that were compromised and others that were over emphasized. In the desire to protect the public from harm, individual liberties were at times unnecessarily compromised. Restrictions were sometimes disproportionate to the level of harm. Situations of inequity were evident across all three themes. Limited attention was paid to the value of reciprocity in providing support to patients whose visitors were restricted. There was often a perceived lack of transparency in communications from the Ministry to general public; from the Ministry to facilities; from facilities to staff, patients and visitors; and from staff to patients and visitors. The focus on restricting visitors resulted in situations of stigmatization including the labelling of all visitors as "nasty" and "noncompliant." Personal information was on occasion released to persons who did not require this information. In the context of future public health emergencies in outbreak conditions and in an attempt to avoid similar unfavourable outcomes, these ethical values need to be explicitly woven into guidelines and policies related to visitor restrictions.

Guidelines for Developing Policies regarding Visitor Restrictions during a Public Health Emergency

The following guidelines for developing policies regarding visitor restrictions during a public health emergency in outbreak conditions flow out of the important ethical values (see Appendix A) identified previously. In the following section, a sample policy that we developed that incorporates these value-based guidelines is outlined. This policy is patient-centred rather than disease specific. Its application is not limited to an infectious outbreak of SARS, rather it is intended to direct visitor restrictions in the context of any public health

emergency in outbreak conditions. In a patient-centred model the patient's needs are considered foremost. The policy is based on the assumption that visitors will adhere to necessary infection control precautions.

Equity

1. To minimize inequities across facilities, a system-wide approach to visitor restrictions should be implemented.
2. To minimize inequities within and across facilities, a shared understanding of the meaning of terms such as imminently dying, terminally ill, critically ill, and serious or significant procedure/treatment should be developed.

Individual Liberty

1. The least restrictive option for patients and visitors should always be chosen.
2. Whenever possible and appropriate, patients (or their substitute decision makers if appropriate) should be asked to identify whom they would like as their visitors. If the patient is uncomfortable and does not wish to inform friends and family members that they are restricted from visiting, this responsibility should be assumed by the appropriate healthcare provider in the institution.

Privacy

1. All visitors should be privately screened at the entrance to the facility.
2. Personal information of patients, visitors, and staff should be maximally protected. Only that information which is needed to protect the public from harm should be released.

Proportionality

1. For certain populations (i.e., terminally ill or imminently dying, critically ill, pediatric patients, patients in labour), the benefits of unlimited visitation by immediate family and/or significant others outweigh the harms associated with strict limitations to visitors and accommodations should be made.

2. Similarly, for patients undergoing a serious or significant procedure/treatment (e.g., open heart surgery, chemotherapy, cardiac catheterization) or patients whose ability to understand is limited due to language, other communication barriers or decreased capacity, the benefits of limited visitation by a partner or significant other outweigh the harms associated with strict limitations to visitors and accommodations should be made.

Protection of Communities from Undue Stigmatization

1. Caution to avoid undue stigmatization of individuals or groups should be taken.

Protection of the Public from Harm

1. Movement of visitors within the hospital must be limited.
2. Visitors must adhere to the necessary infection control precautions.
3. Visitors should be instructed to contact the hospital's infection control and public health unit if they develop symptoms after visiting the facility.
4. Visitors should refrain from visiting the hospital if they are feeling unwell.

Reciprocity

1. Whenever possible, in the context of visitor restrictions, alternatives to in-person visiting should be explored and implemented. Telephone service should be made freely accessible to all patients. E-mail is another readily available alternative that could be utilized. Other technologies such as video telephones and videoconferencing via the computer may become viable alternatives in the future.
2. Procedures for dropping off correspondence and care packages for patients and delivery of same to patients should be put in place.

Transparency

1. Clear and consistent information about visitor restrictions and the rationale for those restrictions needs to be communicated to patients, visitors, staff, and the public through a variety of means (e.g., e-mail, bulletin boards, newspaper, television, radio, entrances to facilities).

2. If the patient has an infectious disease or is under investigation for an infectious disease, visitors need to be informed of the nature of the illness, the risk of contagion and the necessary precautionary infection control measures that must be taken. Visitors need to be informed that exposure to the patient could result under some circumstances in quarantine.

Sample Visitor Policy for a Public Health Emergency

Patient Categories	Number of Visitors	Length of Visitation	Exceptions to Policy
Is the patient terminally ill or imminently dying?	immediate family and significant others*	unlimited	1. If the risk of contagion from the patient is low, visitation may be extended to other family members and friends on a limited basis.**
Is the patient critically ill (i.e., intensive care unit)?	immediate family and significant others*	as per intensive care unit policy	1. If the risk of contagion from the patient is low, visitation may be extended to other family members and friends on a limited basis.**
Is the patient a pediatric patient?	parents	unlimited	1. If the risk of contagion from the patient is low and the length of stay is greater than 2 weeks, visitation may be extended to other family members (e.g., siblings) and friends on a limited basis.**
Is the patient in labour or postpartum?	partner or significant other*	unlimited	1. None.
Is the patient undergoing a serious or significant procedure/treatment (e.g., open heart surgery, chemotherapy, cardiac catheterization)?	partner or significant other*	limited to 2 hours before, length of procedure/treatment, and 2 hours following procedure/treatment	1. If the risk of contagion is low and the length of stay is greater than 2 weeks, visitation may be extended to partner or significant other* on a limited basis.**
Is the patient a long-term care resident?	partner or significant other*	limited to maximum of 2 hours per week at a time specified by hospital/unit	1. None
Is the patient's ability to understand what is happening limited due to language, other communication barriers or decreased capacity?	partner or significant other*	limited to maximum of 2 hours per week at a time specified by hospital/unit	1. None.
All other patients	no visitors		1. If the risk of contagion is low and the length of stay is greater than 2 weeks, visitation may be extended to partner or significant other* on a limited basis.**

*as defined by the patient or substitute decision maker if appropriate; if the patient or SDM is uncomfortable and does not wish to inform friends and family members that they are restricted from visiting, this responsibility should be assumed by the appropriate healthcare provider in the institution

**limited basis: 2 hours per week at a time specified by hospital/unit

Bibliography

Armstrong, S. (2003). Critical care. Chatelaine, September, 130-138.

Coughlin, C. (2002). Open visiting vs. safety. Journal of Nursing Administration, 32(12), 609-610.

Emanuel, E. J. (2003). The lessons of SARS. Annals of Internal Medicine, 139(7), 589-591.

Giganti, A. W. (1998). Families in pediatric critical care: The best option. Pediatric Nursing, 24(3), 261-265.

Harris, J., & Holm, S. (1995). Is there a moral obligation not to infect others? British Medical Journal, 311, 1215-1217.

Lonergan, B. J. F. (1973). Method in Theology (2nd ed.), London: Herder and Herder.

Mason, D. J. (2000). Families: In the way? American Journal of Nursing, 100(2), 7.

Messner, R. L. (1996). Visiting hours: What's really best? RN, 59(10), 27-30.

Meyers, T. A. (2000). Why couldn't I have seen him? American Journal Of Nursing, 100(2), 9.

National Advisory Committee on SARS and Public Health. (2003). Some legal and ethical issues raised by SARS and infectious disease in Canada. In Renewal of Public Health in Canada, pp.163-181.Ottawa: Health Canada.

Nicholson, A. C. et al., (1993). Effects of child visitation in adult critical care units: A pilot study. Heart & Lung, 22(1), 36-45.

Quinlan, B., Loughrey, S., Nicklin, W., & Roth, V. R. (2003). Restrictive visitor policies: Feedback from healthcare workers, patients and families. Hospital Quarterly, 7(1), 33-37.

Ramsey, P., Cathelyn, J., Gugliotta, B., & Glenn, L. L. (2000). Restricted versus open ICUs. Nursing Management, 31(1), 42-44.

Singer, P. A., Benatar, S. R., Bernstein, M., Daar, A. S., Dickens, B. M., MacRae, S. K., Upshur, R. E. G., Wright, L., & Shaul, R. Z. (2003). Ethics and SARS: Lessons from Toronto. British Medical Journal, 327, 1342-1344.

Upshur, R. (2003). Hard choices. Canadian Healthcare Manager, October 2003, 35-38.

Appendix A: Definitions[1]

Equity – dealing fairly and equally with all concerned

Individual Liberty – the quality or state of being free, the power of choice

Privacy – freedom from unauthorized intrusion

Proportionality – assigning a proper or equal share to attain balance or symmetry

Reciprocity – to give and take mutually, returning in kind

Transparency – free from pretense or deceit, readily understood

[1]Merriam Webster Dictionary (2003). Available on-line at http://www.m-w.com/dictionary.htm